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ABSTRACT

The booklet is intended to help parents deal with an autistic child. A special note to parents of newly diagnosed children precedes answers to four questions commonly asked by families. A parent passes on suggestions for living with autism, including advice to refrain from guilt and join a local support group. Parents are urged to consider their own mental (knowledge and expectations), physical (stress and energy level), and emotional well being. Parents are advised to understand their rights and learn to keep records, among other suggestions. Hints for parental survival range from paying attention to one's own health to responding to their children in a quick, consistent, and predictable fashion. Ways to avoid excessive guilt are noted, and a parents' story of their experiences is offered as encouragement. (CL)

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PRACTICAL SUGGESTIONS FOR PARENTS OF CHILDREN WITH AUTISM

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"YOUR CHILD HAS JUST BEEN DIAGNOSED AUTISTIC . . ."

By: Dr. Carolyn Thorwarth Bruey

Your suspicions have finally been validated; your young child is indeed autistic. As you begin to seek help from the professional community — whether that means psychiatrists, psychologists, educators, or other parents of autistic children — you are especially vulnerable to misunderstanding, confusion, and frustration. The present article intends to outline certain key issues which pertain to parents of newly-diagnosed children as well as suggestions to effectively insure that your needs are being met.

RELEVANT ISSUES:

There are certain issues which many professionals and parents of autistic children tend to forget: of utmost importance is the fact that parents of newly-diagnosed autistic children have the right to hope. Not only the somewhat naive hope that accompanies the early shock of learning their child is autistic (i.e., hoping for an immediate "miracle cure"), but also the valid hope that scientific research will someday discover the organic causes of autism coupled with effective medical treatments. We are still in the 15th century regarding the treatment of autism; it is not beyond the realm of possibility that the autistic toddlers of today will be recipients of effective medical procedures in the future.

A second major concern is that we professionals need to remember that our primary goal should be to support and suggest rather than impress. Too often we get caught up in the role of "expert on autism," thereby ignoring many needs of the parents of newly-diagnosed autistic children. We spout our jargon and knowledge, while these parents are still attempting to come to terms with the most basic aspects of having an autistic child. Overloading you with verbiage regarding the latest techniques, or reviewing the relative advantages of "aversive" versus "overcorrection," does little to meet your needs. You will have more than enough opportunity in the future to learn the technical side of having an autistic child; right now your needs may be more of an emotional nature.

WHAT TO DO: Considering the points outlined above, the following strategies are suggested:

1. Continue to hold a realistic degree of hope. Listen to professional and other parents of autistic children, for their expertise and experience will almost certainly be helpful. However, do not become so immersed in their "war stories" or excessively gloomy prognoses that you are no longer an effective parental advocate for your child.

2. Ask professionals to define their terms. We often become so engrained in our professional/parent communities that we forget the lay population has never heard of "self-stimulation," "primary reinforcement," "NSAC," etc. Unless you fully understand these words and phrases, such information merely causes you to feel confused and inadequate.

3. Do not ignore your own or other family member's emotional needs. Perhaps you are still grieving over the loss of your visions concerning your autistic child; or maybe you just need someone to listen to you with a sympathetic ear. These are natural responses and seeking professional help should not be seen as an indication of "pathology." After all, as Helen Featherstone writes, families of the developmentally disabled are just "ordinary folks faced with an extraordinary situation." There are many professionals in the field who can help you adjust to the problems inherent in having an autistic child.

In sum, we professionals often forget that parents of newly-diagnosed autistic children tend to have special needs as compared to parents who have been "in the game" for years. Your first step is to examine and acknowledge your own individualized needs; your second is to be honest and straight-forward when describing these needs to professionals. Such openness and honesty will keep us on our toes, thereby assuring that your needs will be met during this especially difficult period of your life.

Reprinted from the NJSSAC Newsletter *Lifeline*.

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QUESTIONS FAMILIES FREQUENTLY ASK

By: Dr. Carolyn Thorwarth Bruey

I. Issue: Parents Ask, "AM I AT FAULT?" For many years, professionals hypothesized that autism was caused by cold, unfeeling parents. Contemporary research indicates clearly that individuals with autism exhibit abnormalities in the Central Nervous System; unfortunately, much of the lay population continues to hold onto the outdated notion that parents cause autism, thus leading to underlying doubts on the part of the parents of the developmentally disabled.

Answer: Knowledge is the best solution. The more parents understand the current research regarding autism, the better they can quell their own doubts as well as inform others who callously imply blame. A local college library can offer many journals which include research on Autism, most notable The Journal of Autism and Developmental Disabilities.

II. Issue: Siblings Ask, "WHAT ABOUT ME?" Having a developmentally disabled family member demands a tremendous amount of energy and attention. At times, non-developmentally disabled siblings feel ignored or jealous as a consequence. Almost invariably, such feelings are compounded by guilt (i.e., "How can I feel angry when he/she can't help being developmentally disabled?")

Answer: Parents need to be open to siblings' reactions. They cannot assume that "no news is good news." If non-developmentally disabled youngsters do not initiate conversations regarding their developmentally disabled sibling, parents should broach the subject themselves. Often, parents find that siblings share many of their own feelings of frustration, guilt, anger, etc.

III. Issue: Parents Ask, "WHAT DO I DO NOW?" Parenting is a tough enough job without the added stress of having a developmentally disabled offspring. After all, parenting books rarely address such behaviors as self-stimulatory actions, self-abuse, or aggression. As a consequence, parents of the developmentally disabled often feel incompetent and at a loss.

Answer: Uncommon behaviors call for uncommon parenting strategies. Parents need to contact professionals in the field who can provide training in techniques which have proven effective. These techniques *do*

exist, and they can help parents of the developmentally disabled to feel more competent in their role as parents of a developmentally disabled youngster.

IV. Issue: Spouses Request, "CAN WE HAVE FIVE MINUTES TO OURSELVES?" When offspring are young, parents expect to put their "private times" on hold to an extent. However, when a family member is developmentally disabled, "on hold" tends to become "unobtainable." Baby-sitters who are willing (let alone capable) of handling a developmentally disabled youngster are few and far between, and parents frequently find that they forego time to themselves because "in the long run, it's just easier."

Answer: It is essential to maintain a supportive relationship between husband and wife. Private times help to achieve this goal, as well as remind parents that there are other aspects to their lives beyond the fact that they happen to have a developmentally disabled child. Fortunately, services such as respite care and professional training for babysitters are becoming more common. Parents need to take full advantage of these services to help balance the needs of all family members.

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"SO NEAR AND YET SO FAR: LIVING WITH AUTISM"*

By: Carmen Pingree

I hardly claim to have all the answers on how to manage with a handicapped child. But after considering my own experiences, I might suggest a few things that one facing similar circumstances can do:

Accept Reality: It is normal to go through a period of denial and grief. But the sooner we dry our tears over the child who might have been and get on with the business of what to do with the child who is, the sooner some sense of balance will be restored to our lives. No one escapes this life without trials — ours are just a little more visible than some. Self-pity wastes valuable energy needed to help the child.

Don't Feel Guilty: Autism is a biological disorder and is not brought on by something the family may have done to the child. Likewise, having a child with any sort of handicap is not a punishment for transgression. Make sure other members of the family understand this.

Find A Good Program For Your Child: When he or she begins to progress, your whole outlook will change. Look for a structured setting where your child's strengths and weaknesses will be assessed individually. A one-on-one behavioral treatment plan tailored to decrease negative behavior and build on strength is essential. Once you've found this program, consistently follow through at home. Work in the classroom or visit often, if possible, so that you become part of the teaching team.

Join A Local Support Group: Other parents and dedicated professionals are invaluable sources of information and moral support.

Be Active In Community Efforts For Autistic Children (or those with other problems): You have the ability to make important contributions. Similarly, the work and friendship of others in the community will enrich your life.

Provide A Positive Learning Experience For All Family Members: Family discussions can help family members understand their own feelings better and can help them develop empathy and compassion for others with dif-

ficult problems to face. Children can participate in a variety of therapy programs according to age and ability. Be careful to arrange quality time with your other children away from the autistic child so that they do not become resentful.

Take Care Of Yourself: As the parent, you are the key to the family's well being. Make time to do something enjoyable and personally fulfilling. If you feel the need for professional counseling, get it. An autistic child puts significant stress on the marriage relationship, so pay close attention to what is happening between yourself and your spouse.

Keep Grandparents Informed And Involved: They are concerned about both the child and his parents. They also can be a source of tremendous strength and comfort.

Discuss Your Child's And Your Own Special Needs With Neighbors And Friends: Talk about your situation with neighbors and friends so they can understand and be supportive. Unless you open the door, most will be afraid to do or say anything because they are afraid of doing the wrong thing. Give them a chance!

No Matter What Else You Must Sacrifice, Hold On To Your Sense Of Humor! When your physical energy is totally spent, and your nerves are raw, it may be the only thing that can relieve the tension.

GOOD LUCK TO ALL OF YOU AS
YOU FACE THIS CHALLENGE.

*Reprinted from the January/February, 1986, Issue of the Advocate, The Newsletter of the National Society for Children and Adults with Autism.

SURVIVAL TIPS FOR PARENTS OF CHILDREN WITH AUTISM

By: Dr. Carolyn Thorwarth Bruey

Remember when you were in the Boy/Girl Scouts and you were provided with all the necessities for survival prior to any camping trip? Unfortunately, infants do not come with instruction booklets, nor do hospitals hand out packages of survival tools as parents journey forth into the world of parenting. When the infant turns out to be a developmentally disabled child, parenting becomes all the more difficult. As a consequence, there may be times when parents find themselves feeling at the end of their rope. The present brochure intends to provide a general strategy for first assessing the source of your difficulties and then subsequently developing strategies to improve your quality of life.

It is first contended that all personal difficulties can be categorized into one of three areas: Problems generated by changes which need to be made in the mind, the body, or the emotions. Before you can successfully solve any difficulty you may be experiencing due to your developmentally disabled child, it is essential to assess clearly the source of your distress. Only through such a clear assessment can you help yourself improve the situation. This is by no means to imply that the presence of a developmentally disabled child does not place extra demands and pressures on parents; anyone who has interacted with families of the developmentally disabled cannot help but acknowledge the pain and stress inherent in having an autistic child. But, given the fact that your child is autistic, it is essential to react to that fact in the most adaptive means possible.

(1) THE MIND

Recent psychological research and application has spent a good deal of time assessing people's cognitions and belief systems as a means of developing strategies to relieve stress. Families of the developmentally disabled tend to inadvertently increase stress by holding onto particular beliefs which heighten pressure. Almost invariable, these beliefs involve unrealistic expectations of yourself, your developmentally disabled child, or other family members. Questions to ask yourself include: Although I know that my child progresses slowly, is there a part of me which expects a faster-paced development? Do I feel that I have failed in some way if I do not

spend many hours teaching my child new skills or collecting reams of data? Do I expect myself to fulfill the needs of my other children and my spouse perfectly while limiting the extent to which I address my own needs? Do I expect my spouse to spend his or her every free minute with our developmentally disabled child? Am I impatient when my other children do not accept their developmentally disabled sibling completely? These questions are posed in the extremes; however, many parents of developmentally disabled youngsters harbour them to some extent. Unrealistic expectations — especially of yourself — can lead to unnecessary stress and frustration. It is important to assess your beliefs and expectations in order to determine if they are in fact realistic.

Another aspect of the "Mind" category is knowledge. It is impossible to gain too much knowledge regarding your child and techniques to improve his or her behavior. Parent training can be a viable means of learning skills which can decrease the stress in your household. Gaining knowledge about experiences of other parents of developmentally disabled children can help you to realize that there are other people who have felt similar frustrations and pressures. Do not be afraid to ask for clearer explanations if a parent or professional does not take the time to make sure you understand.

(2) THE BODY

The second area to assess is your physical reactions to having a developmentally disabled child. Everyone experiences stress differently on a physical level. One person may begin to feel a queasy stomach, while a second individual may feel pain behind their eyes. All experiences of stress include a physical component; conversely, if one is thoroughly relaxed, it is impossible to feel stressed. Therefore, it is important to assess what your own physical cues are during the initial phase of stress such that you can deliberately guide yourself to relax.

How does one relax? There are many methods of "forcing" yourself to relax. Some parents find that common techniques such as taking a leisurely bath, listening to music, or going on a walk are useful means of decreasing stress. Or, if you are alone and must supervise your developmentally disabled child, take deep, slow breaths and deliberately relax those parts of your body which are feeling tight. Although many of these activities are known to be effective means of relaxing, parents rarely schedule them into their daily routines. Instead, they insist that the time be spent with their autistic child or with the other children "because they get ignored so much." In the long run, the time you spend relaxing will bene-

fit all members of your family, for you will not be able to give them quality interactions if you are overstressed and exhausted.

A second subcategory of the "Body" area is energy level. Having an autistic child demands an incredible amount of energy, leaving parents feeling completely drained. At these times, parents need to take advantage of any support systems they may have in the community or within the family. In-laws, siblings, and neighbors can all be taught to be effective babysitters. Before you cry, "Oh, but they have their own lives, would not be able to handle it," etc., please reread the sections above on "expectations." Allow yourself to request support from others rather than expecting yourself to be super-human. And, of course, the recent development of respite care programs is an effective means of decreasing stress.

(3) THE EMOTIONS

Parents of developmentally disabled children experience a wide range of emotions, including both positive ones (e.g., joy when your child uses his first sign), as well as negative ones (e.g., frustration when your child continues to respond incorrectly to an instruction). Although parents of autistic children are not more prone to experience any abnormal emotions as compared to the general population, research has shown that the presence of an autistic child does add an extra pressure which can cause parents to experience certain normal emotions more intensely and frequently.

The emotions cited most frequently by parents of autistic children are guilt, sadness and feelings of being an ineffective parent. Almost invariable, these emotions can be linked to some of the problematic beliefs outlined in section one. For instance, parents often feel guilt because they hold an invalid belief that the disability is their fault. Or, another parent may feel ineffective because they "only" spent an hour teaching their autistic child that day. Again, it is essential to assess the ways in which your beliefs may be causing unnecessary problematic emotions.

Having an autistic child is inherently sad to some extent; it would be maladaptive to pretend that you are not feeling a certain amount of regret due to your child's disabilities. Similarly, it is normal to experience bouts of frustration and anger due to your child's problems. If you are feeling overwhelmed by these emotions and are unable to alleviate the stress on your own, it may be helpful to contact a professional who specializes in treating families of the developmentally disabled. Therapeutic intervention is by no means a sign of failure, and avoiding professional help for a prolonged period of time will only exacerbate the situation.

All in all, having an autistic child can be a challenging experience. Unfortunately, there are no easy answers. However, the strategies listed above should prove useful in helping make the experience a less stressful one.

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SUGGESTIONS FOR PARENTS*

1. You are the primary helper, monitor, coordinator, observer, record keeper and decision maker for your child. Insist that you be treated as such. It is your right to understand your child's diagnosis, the reasons for treatment, and recommendations for educational placement. No changes in his treatment or educational placement should take place without previous consultation with you.

2. Your success in becoming as well informed as you will need to be to monitor your child's progress depends on your ability to work with the people who work with your child. You may encounter resistance to the idea of including you in the various diagnostic and decision-making processes. The way you handle that resistance is important: Your best tool is not the angry approach, but the gentler art of persuasion. Stay confident and cool about your own abilities and intuitions. You know your child better than anyone else could. You are, obviously, a vital member of the team of experts.

3. Try to find, from among the many people whom you see, a person who can help you coordinate the various diagnostic visits and results. Pick the person with whom you have the best relationship, someone who understands your role as the principal monitor of your child's progress throughout life and who will help you become a good one.

4. Learn to keep records. As soon as you know that you have a child with a problem, start a notebook. Make entries of names, addresses, phone numbers, dates of visits, the person present during the visits, and as much of what was said as you can remember. Record the questions you asked and the answers you received. Record any recommendations made. Make records of phone calls too; include the dates, the purpose, the results. It is best to make important requests by letter. Keep a copy for your notebook. Such documentation for every step of your efforts to get your child the services he needs can be the evidence which finally persuades a program director to give him what he needs. Without concise records of whom you spoke to, when you spoke to him, what he promised, how long you waited between the request and the response, you will be handicapped. No one can ever be held accountable for conversations or meetings with persons whose names and titles you do not remember, on dates you cannot recall, about topics which you cannot clearly discuss.

5. Make sure that you understand the terminology used by the professional. Ask him to translate his terms into lay language. Ask him to give examples of what he means. Do not leave his office until you are sure you understand what he has said so well that you can carry the information to your child's teacher, for instance, and explain it to her in clear, understandable language. (Write down the professional terms too. Knowing them might come in handy sometime.)

6. Ask for copies of your child's records. You probably will not get them, but you could ask that a tape recording be made of any "interpretive" conference. It is very hard to remember what was said in such conferences.

7. Read. Learn as much as you can about your child's problem. But do not swallow whole what you read. Books are like people. They might be offering only one side of the story.

8. Talk freely and openly with as many professionals as you can. Talk with other parents. Join a parent organization. By talking with people who "have been through it already," you will receive moral support and will not feel quite so alone. Get information from parent organizations about services available; about their quality. But bear in mind that a particular program might not help your child even though it has proved helpful for another child. Visit programs if you have the time and energy to do so. There is no substitute for firsthand views.

9. Stay in close touch with your child's teacher. Make sure you know what she is doing in the classroom so that, with her help, you can follow through at home. Share what you have read with her. Ask her advice and suggestions. Get across the idea that the two of you are a team, working for the same goals.

*Reprinted from: *A Guide for Parents Through the Maze of Regulations Governing the Special Education of Disabled Children, New York State, January, 1985.*

HINTS FOR PARENTAL SURVIVAL*

Over the years, coping on their own and sometimes with professional advice, parents have found a number of things they can do to help themselves survive. One of the most valuable is to join a parent support group where they don't feel so isolated and can share problems and feelings with people who have been down the same road. This is also an excellent source of information on the types of resources and assistance that may be available. Other survival tips often mentioned by parents (and professionals) include:

- Work to develop a structured routine for your child's care. Your responses to your child should be predictable and consistent. Research and experience show that autistic children do better when there is order in their lives. Remember, though, that this does not mean protecting them from the unexpected. They have to learn to cope with that too.
- Avoid blaming or criticizing your spouse for the way your child is being handled.
- If your child is disruptive at night, take turns with your spouse in caring for him. Sometimes wrapping a child snugly in a blanket or rocking him is calming. The goal is to teach him to sleep or at least stay in his room at night.
- Don't neglect your own health, since poor health and exhaustion affect your ability to cope. This means eating properly, getting enough exercise and sleep, and finding time for recreation away from the demands of your child.
- Parents and other children should work together to provide needed respite time for each other.
- Arrange for outside help so you have time together to visit friends, have dinner out, see a movie or do whatever you find relaxing and enjoyable.
- Start training your baby-sitters early, before they are actually needed. Pay them to be around the house for a few afternoons while you are there, then take yourself away a little, to do the ironing or write a few letters. If things go well, leave the house only for a few minutes at first. If they still go well, you have a real baby-sitter who can train her successors in just the same way.
- Take your child shopping in small stores before you try a supermarket.

There is less motion and confusion for your child and there is a chance for the shopkeepers and the other patrons to learn to know your child and make allowances for his behavior.

- Don't hide your child. The more people know about him, the easier your social life will be and the less you will have to explain. Try to get autism onto the agenda of the PTA and other local organizations. *Share* what you know with teachers and other parents.
- No matter how discouraging things may look, try to maintain your sense of humor. Any disaster is lightened by a little laughter. Enjoy the humor that your child brings!
- Daily routines should be organized so as to provide time and attention for other children in the family. It is important that they not feel unloved or neglected. They must gradually be taught why their brother or sister requires more time and attention, and how they can help.
- There should be safe places for the autistic child — a room indoors where he can be left safely and perhaps a fenced-in place in the yard.
- Since autistic children have no sense of danger, it may be necessary to lock doors, hide keys, and childproof dangerous windows.
- It is important not to let the temper tantrums caused by changes in routine dominate your life. Even if screams accompany your child's attempts to keep his world from changing, some obsessive rituals and routines can be broken by ignoring them.
- The harder you try, the better your child will probably do. But remember, there is no magic cure. If you are trying and your child progresses slowly or not at all, it is not due to your failure to mount some gigantic or super-devoted effort. The child has autism, that's all. Do the best you can and then face the fact that you can't and shouldn't sacrifice your life or your family's for the one child. Keep a sense of proportion. A family's life should not revolve forever around one member.
- Hyperactivity may be lessened by restricting the child's movements, by teaching him to sit in a chair while something is being taught. Letting him work off the energy often only seems to make the hyperactivity worse. Give him something to do that he enjoys.
- Compulsive behavior can be controlled if the child is restricted in his ability to carry out the behavior. The more he is stopped or guided away from participating in these activities, the less compulsive he becomes.
- Tantrums are usually a means of getting out of something, or of getting

something. The demands and the tantrums should be ignored so that the child has no audience. Afterwards, see that the request or instruction that prompted a tantrum is obeyed.

- Sometimes a huge reaction to a request is not really a tantrum, but a sign that the child knows he can't comply. Then you must change your strategy.
- There are many strategies for dealing with tantrums. The main thing is not to make a big fuss about them, since that tends to reinforce the behavior. Some parents and teachers have "time-out" rooms where the child is placed until he calms down, but others claim that what provoked the tantrum in the first place is the child's feeling of too much pressure on him, so he throws the tantrum in order to be left alone for a while. There is no standard procedure. Try various responses, in cooperation with the child's teacher, to see what works best. Stick with that as long as it works, then try something else.
- Autistic behaviors can sometimes be eliminated by teaching some other behaviors. Example: an autistic child can't flap his hands and arms if he learns to keep his arms at his sides while walking and on his knees while sitting.
- If an older child is excited and asks the same question again and again, try insisting on written questions and giving written answers. This can have a wonderfully calming effect.
- Remember, behavior problems do not develop overnight and they won't disappear immediately. Sometimes the problem gets worse before it gets better. The lack of attention to a tantrum may cause a child to redouble his efforts before he decides it won't work anymore, so don't give up!
- Autistic children make the most progress in an environment of order, structure and logic.
- You need to be quick, consistent, and predictable in your responses. Permissiveness does not work with autistic children. You are not helping them when feelings of love and compassion lead you to let them get away with bad behavior.
- Don't expect too much too soon. Working with an autistic child is slow and often frustrating. It requires great patience.
- Austic children need time (but not too much of it) and a place to be alone, for respite from a confusing world.
- As much as possible, autistic children need to be kept occupied and in

touch with the world around them. Even young children can learn to cooperate and carry out simple tasks.

- Since autistic children have a very poor sense of danger, they should be taught to respond immediately to "stop" or "no." Sometimes this needs to be taught by physical restraint.
- The autistic child should not be given a chance to ignore instructions or refuse to follow them. Since too may words are confusing, instructions should be short and simple and given as the child is being guided. Example: "Go outside," should be said as the child is being guided outside.
- Don't assume your child understands what you are saying. Words need to be reinforced by gestures and guidance, by facial and bodily expressions.
- Directions should state only what needs to be done, leaving no room for choice. Example: "Dinner," not "Are you ready for dinner?"
- Do not attempt to supply all your child's needs; rather let him try to say or show what he wants and promptly reward efforts to communicate.
- The parent-therapist needs to be in control. Tantrums, hyperactivity or withdrawal must be overcome and the child must be required to pay attention.
- Eye contact is essential as an aid to communication. This can be taught by sitting in a chair facing your child and, as you command "look at me,' hold the child's chin and gently turning his face. The child should be rewarded. The exercise should be repeated and, in time, the prompting gradually reduced until he turns automatically at the command "look at me."
- Eye contact should not be over emphasized, however. If you are trying to teach your child to do something, you want him looking at the job, not at you.
- Try to find out the pathway by which your child learns best: sounds, words, touch, even smell. Use it to teach and to open other pathways.
- Autistic children who don't understand language often can learn by "feeling" a skill, by having their arms and hands held and moved through the motions until they can do the job themselves. Eating and dressing can be taught in this way.
- An autistic child needs to be taught to listen. This is done by establishing eye contact, then giving a direction and demonstrating it with a gesture.

Directions should be simple and specific, the gestures easy to understand.

- It is important to go slowly and avoid trying to teach too many skills at once. If a child has trouble progressing or seems agitated, back up and review the steps to be sure they were small enough.
- If your child has achieved success, let him have the satisfaction of his achievement for a while before you raise your demands. If he finally learns to tie his right shoe it was probably a great effort and he probably did it to please you. Tie the left one yourself for a few days.

*Reprinted from: *How They Grow: A Handbook for Parents of Young Children With Autism*. NSAC Bookstore, 1234 Massachusetts Ave., NW, Washington, D.C. 20005, (202) 783-0125

HOW TO GET OFF THE GUILT TRIP*

"Whenever I have meetings with professionals, I often wind up feeling guilty. I know I'm not to blame for my child's handicap, yet I often get the feeling that they (the professionals) think my child would not be handicapped or would do better, if only I were a better parent."

Why Should You Feel Guilty For Trying To Get Help For Your Child? Isn't that why you went to the professionals? To get help for your child? Why should you feel guilty about that? Why should you feel guilty for being concerned about your child's welfare, for wanting the best educational services, the best treatment, the best psychological services?

Why should you feel guilty for looking ahead and trying to plan his future so he can live the best possible life and develop his/her fullest potential? Why should you feel guilty for being worried when things don't go right, and for getting angry when obstacles are thrown in your way?

Why should you feel guilty for expecting professionals to provide the services you are paying for through your taxes? And for getting angry when bureaucrats are not doing their job?

How Does Feeling Guilty Help Your Child?

You Can Stop Feeling Guilty By Acknowledging That:

1. You have the right to get the best possible help for your child.
2. You have the right to insist on quality services for your child.
3. You have the right to get everything you are paying for.
4. You have the right to complain when you don't get what you are entitled to for your child.

Of course you would like to be a better parent. Who doesn't? Everyone — including those who are intimidating you — would like to be better parents and do more for their children. Do you know for certain that they are better parents than you are? Do you know for certain that they would be able to do better with a child like yours? Do you know for certain that they would be more effective in dealing with bureaucracies and with professional guilt inducers? Do you know for certain that they never make mistakes, that they don't ever feel guilty about *anything*?

If you ask yourself these questions — or better yet — ask "them," you will find that the people who are intimidating you and making you feel guilty, are not any better than you are, after all. So why let *them* intimidate *you*?

Don't Waste Time Feeling Guilty. Don't waste time with a lot of "if only's." Start helping your child today. Start helping him/her by being an assertive parent who can get the services your child needs.

1. *Get involved in a parent group.* Write CLOSER LOOK, P.O. Box 1492, Washington, D.C. 20013, for the name and address of your local parent organization, if you're not sure.
2. *Meet and talk with other parents.* Support each other — but don't stop there.
3. *Become an active member of the group* by joing a committee. If there are no committees, form some. (See HOW TO ORGANIZE AN EFFECTIVE PARENT/ADVOCACY GROUP AND MOVE BUREAUCRACIES, published by CCHA)
4. *Join in letter writing campaigns to get better services.* Join in lobbying efforts to get necessary legislation passed and implemented.

Soon You Will Be Too Busy To Feel Guilty. And you will be feeling good about yourself because you will know you are doing everything you can to help your child.

*Reprinted from: *How to Get Services by Being Assertive*,
The Coordinating Council for Handicapped Children
220 South State St., Room 412
Chicago, Illinois 60604
(312) 939-3513

A STORY OF ENCOURAGEMENT

(Written by the parents of a child with autism)

We can remember the first time the term "autistic" was used to describe our son. We had been concerned for some time that he wasn't talking and we had just begun a long battery of tests in search of a cause. After the results of a hearing test were inconclusive, his pediatrician suggested that Tommy may be autistic. By this time, at age three, he had already undergone several tests and when we heard autism mentioned it seemed like a possibility, not a threat. We were, after all, trying to discover the nature of his condition and at this point we were willing to accept anything that would provide a point of departure, a place to start, a beginning to an end to his problem. The word autism was a bit startling but not really horrifying. It seemed an answer, not a curse. It wasn't until later that we found many new meanings to this word.

Tommy had a normal birth and a very normal first 18 months. He had a pleasant smile and an easy-going nature. Everyone commented what a doll he was and how good natured he was. At eight months he said his first word, "mom." He babbled and cooed appropriately until he was about a year and a half old when he became completely silent. Whenever we tried to elicit any kind of verbal response from him, he would retreat into his own world. He averted his gaze. He had no interest in other children, including his older brother. He paid no attention to television. He was never interested in seeing himself in the mirror. He sometimes acted as if he were deaf.

We, of course, noticed these behaviors but thought them normal. Tommy was, in our minds, a "thinker" . . . a strong willed, stubborn, independent little boy. He simply "chose" to spend his time in his own way. After all, as many of our best intentioned friends and relatives were to later tell us, "Einstein didn't speak a word until he was five." We decided that he was just a "late talker."

By the age of three it was apparent that his behaviors were not normal and we could no longer deny that he had a problem. With our pediatrician's guidance we began the long, difficult process of going to a myriad of professionals to have our little boy diagnosed.

Although the term autism kept coming up, it wasn't a unanimous diagnosis and we found ourselves siding with those who diagnosed him as any-

thing else. So afraid of having Tommy labled autistic, we refused to share the results of one professional's test with another. We wanted each to arrive at their respective conclusions independently.

Our knowledge of autism was restricted to what we had been taught in abnormal psychology class fifteen years back. We knew that it was not understood and that psychology and modern medicine had no answers . . . no cure. We remembered that the cause was unknown. And mostly we remembered, quite vividly, the picture of the young boy with the blank stare all alone in a room. He was suffering from autism, an affliction with no cure. His was in a world that no one could enter. A world full of loneliness. The picture, and the caption below it had a clear message. There is no hope for this child.

This was not the future we had planned for our son. How could we have been so wrong? We felt Tommy had tremendous potential if it could only be tapped. We could see it in the logic of his play and in the creations he made with building blocks, Lego, Tinker Toys, etc. We could see it in his smile. We could see it in his eyes. To us a diagnosis of autism was the equivalent of a death sentence for our son. Everything that we read or heard about autistic children offered no hope for their future. How could we possibly accept this fate for our little boy? The term austim had now become horrifying to us. We spent many hours in tears, "mourning the loss of our normal child."

Our pediatrician had recommended a speech therapist to us, and it was she who finally convinced us to accept the diagnosis and to get Tommy the right kind of help immediately. She stressed the need for a very specific behavioral program to combat these behaviors.

Now that we accepted the fact that Tommy is autistic, we had to begin the task of finding the best educational setting we could for him. We knew we had to accomplish this quickly, because Tommy's best chance depended on getting him into an appropriate program at an early age.

During the next several months, we contacted many different people involved with autistic children. In short, we enlisted the help of anyone who could aid us in our quest to get Tommy into the program that he needed. Sleepless nights and lengthy phone calls became a way of life for us. As we look back on this time, we wonder how we got through it. Armed with the knowledge we had of the need for early intervention and the importance of placement in the right program, we were able to sustain ourselves during the most difficult time of our lives.

This story has a happy ending. Tommy started school last September

when he was three years and four months old. Today, almost exactly one year later, he is a completely different child. Most of his "autistic behaviors" are gone. He is now speaking in phrases and his vocabulary increases every day. He loves his big brother and tries to copy everything he does. He knows the letters of the alphabet, can count to twenty, and is starting to read. This August, he attended a regular day care center on a trial basis and did very well. Can you imagine our joy when his teacher told us that he had no trouble adjusting to the school, that he played well with the other children and that he had made a special friend? We cried all the way home, but this time they were tears of happiness. Tommy still has a way to go, but he is making rapid progress. Plans for transition programming are under way.

Accepting the fact that our son was autistic was the hardest thing we have ever had to do, but it was a necessary first step in the process that led to all the progress that he has made. As we watch him happily chase seagulls on the beach, enjoy a newfound friend, or hear him singing a song to himself as he plays in another room, we can't help but wonder where he'd be today if we had wasted precious time denying his autism because of the stigma attached to the term or because of our own fears and prejudices.

Our primary purpose for writing this article was to share our experience with those parents who find themselves facing the same situation that we faced last summer. Emotionally distraught in the beginning, we weren't quite sure where to turn for support. We hope Tommy's story is one of encouragement and that it may help you in some small way.

BASIC RULES
FOR BEHAVIOR MANAGEMENT*

1. **Be Consistent**

   - If you react to behavior x, do it every time.
   - If you ignore behavior x, do it every time.

2. **Follow Through**

   - If you say you're going to do something, do it! Otherwise, don't say it.

3. **Be Positive**

   - Whenever possible, praise your child for good behavior. You can always find something good to say if you just look.
   - Don't attend only to negative behaviors.

4. **Expect the Best**

   - You will get what you expected. Don't accept inappropriate behavior. Expect appropriate behavior from your child and you may be pleasantly surprised.

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BRIEF READING LIST

Available From:

NSAC Bookstore
1234 Massachusetts Avenue, NW
Suite 1017
Washington, DC 20005
(202) 783-0125

#26 Early Childhood Autism. Wing. $12.75

#27 Autistic Children: A Guide for Parents. Wing. $5.95

#77 Reaching The Autistic Child: Parent Training Program. Kozloff. $11.95

#127 Unraveling The Special Education Maze. Cutler. $9.95

#128 How They Grow: A Handbook for Parents of Young Children with Autism. NSAC. $4.00 (parents) $6.00 (others)

#130 Teaching Developmentally Disabled Children: The Me Book. Lovaas. $17.95

#145 The Effects of Autism on the Family. Shopler/Mesibov. $35.00

#150 Brothers and Sisters - A Special Part of Exceptional Families. Powell/Ogle. $16.95

#151 Inside Out. Martin. $10.95

OTHER SOURCES:

DeMeyer, M.K. (1979) *Parents and Children in Autism.* Washington, DC: J.H. Winston & Sons.

Featherstone, H. (1980) *A Difference in the Family.* New York: Basic Books.